Counselling for people affected by cancer: the impact outside a healthcare setting

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Despite there being no formal ethical approval requirements for this project, good practice was adhered to at all stages in the research process regarding anonymity, data protection and sensitivity in handling data.

The manuscript is an honest, accurate, and transparent account of the study being reported and no important aspects of the study have been omitted. Any discrepancies from the study have been explained.

Abstract

Objectives: Study objectives were to measure the impact of counselling for people affected by cancer outside a national or private healthcare setting, such as a hospital or clinic, following treatment, and shed light on the nuances of this by gender, age and cancer status. *Methods:* CORE-10 was used to measure psychological distress amongst a practice-based sample affected by cancer including a comparator group of those who had not yet received counselling. *Setting:* The study was conducted in counselling offices outside a clinical or healthcare setting, both in terms of physical infrastructure, and in terms of funding mechanisms. *Participants:* 158 participants were selected based on the following inclusion criteria: completion of a full set of CORE-10; having completed six sessions of counselling at the time of analysis. *Results:* Results show psychological distress improves for all receiving counselling outside a national or private healthcare setting according to the CORE-10 scores. Those 'affected by cancer' are initially more distressed and benefit more from counselling than 'cancer patients'. In comparison with females, male comparator group scores increase (gets worse) between 'assessment' and 'first' counselling session, before they have received any counselling.*Conclusions:* The paper concludes that counselling 'outside' a healthcare setting appears to be beneficial to anyone diagnosed or affected by cancer. Benefits vary by demographic group and exploring the meaning behind variations requires further, qualitative, investigation.

Keywords: counselling, cancer, community, gender, age.

Introduction

This article adds to existing research examining counselling outcomes for people affected by cancer. Specifically, it shows counselling outcomes for people outside a healthcare setting (post-treatment); for people with a cancer diagnosis and those affected indirectly (close family or friend of a patient) and compares between people of different ages and genders. It presents quantitative data collected by counsellors working for a cancer charity which provides free counselling to anyone affected by cancer. Typically, people are referred to the counselling service through a health professional within the National Health Service (NHS) or through a dedicated support line referral system within the charity. The research uses CORE-10 as a validated screening tool for psychological distress in this setting.

Research into the impact of counselling for people with a cancer diagnosis within a healthcare setting is well established. Hill, Brettle & Jenkins' (2008) study found brief counselling was more effective than routine primary care in the short term, but the findings on long term effects were inconclusive. The study also found Cognitive Behavioural Therapy (CBT) and other forms of counselling to be equal in effect, with the combination of counselling with medication the most effective in terms of lessening psychological distress. Watson, Denton, Baum, & Greer's (1998) randomised control trial of a specialist nurse counselling service for breast cancer assessing physiological morbidity, found counselling reduced distress caused by cancer diagnosis. Spiegel, Kraemer, Bloom and Gottheil's (2007) controlled study goes further by looking at the long-term effect of therapy and hypnosis on patient

survival, and found survival time almost doubled amongst those receiving therapy. Most recently, Sharpe, Walker, Holm Hansen, Martin, Symeonides, Gourley, and Morley (2014) found counselling for cancer patients in a hospital setting to improve;

> *"…*depression, anxiety, pain, and fatigue' and can mean '…better functioning, health, quality of life, and perceived quality of depression care at all time points" (2014, p.1099).

The long-term benefits of counselling for people with cancer have been shown in a longitudinal Swedish study carried out between 1988 and 2000 (Ohlen, Holm, Karlsson. & Ahlberg, 2005):

> "67% of the participants stated that they had received improved understanding of their own reactions and feelings. Nearly half the group (40%) experienced distance to their disease and life situation. Some participants also said that they experienced increased pleasure in life (44%), had more ability to take action (42%), and were less frightened (37%) after the intervention" (2005, p.64).

Omylinska-Thurston & Cooper's (2014) qualitative study into therapy for people with primary cancer within an NHS psychology service found benefits for patients include forming relationships with their therapist, normalisation and problem solving. However, little attention has been given to exploring the impact of no-cost

counselling outside a healthcare setting. This type of research is important because evidence shows people with a cancer diagnosis can feel isolated after formal treatment and support has ended as;

> "It acts as a reserve and resource to blunt the effects of stress or to enable and individual to cope more effectively when it is at high levels" (Taylor, Falke, Shoptaw & Lichtman 1986, p. 1).

This adds weight to the value of research into counselling outside a healthcare setting.

Little research exists comparing those with cancer and those affected by cancer. Pitcealthly & Maguire's (2003) study, looking at the impact of cancer, shows an increase in tendency towards psychological problems amongst those close to the patient. Additionally, Grunfeld, Coyle, Whelan, Clinch, Reyno, Earle and Glossop's (2004) research into family caregivers for dying cancer patients showed similar proportions of caregivers and patients were depressed and more caregivers than patients were anxious. Employed caregivers also experienced adverse impacts on work and adverse financial effects due to the cost of caring.

In response, this paper presents practice-based data from cancer patients and carers receiving counselling outside a healthcare setting within dedicated counselling offices or aboard a mobile cancer support unit in various outreach

locations across Wales. The aim is to determine and compare any reduction in psychological distress among cancer patients and carers receiving counselling outside a healthcare setting. The method of doing this was by means of a standardised questionnaire administered before, during and after a course of counselling.

Methods

Design

The study uses a pre- and post-intervention design measured with a standardised questionnaire, repeated at first, middle and final counselling session. The results presented in this paper were captured using the validated tool CORE-10; a brief component of the CORE-OM and CORE-System to measure counselling delivery. While research exists on the use of CORE-10 (Barkham, Bewick, Mullin, Gilbody, Connell, Cahill…and Evans, 2013), little is publicly available on its use in the field of cancer.

In terms of its effectiveness, Barkham et al's (2013) study on the development of CORE-10 found it useful as an instrument for use with people presenting 'common mental health problems'. Evans, Mellor-Clark, Margison, Barkham, Audin, Connell, & McGrath (2009) also found CORE-10 to be an acceptable form of measurement in routine evaluation for the following reasons:

> "The measure is brief and acceptable to clients and therapists. It covers wellbeing, problems/symptoms, life functioning and risk to self and others. It is easy to score by hand and is computer scan-able. It measures individual differences on entry into therapy and change" (Evans et al. 2009, p.1).

More recently, Ragan, Pugh, Degnan & Berry (2016) found CORE-10 to have a high internal consistency in their study on coping, though control and psychological distress. However, Burke's (2013) assessment of CORE-10's effectiveness on patients attending a low-cost therapy clinic, found direct contradictions between respondent's CORE-10 results and findings from a qualitative investigation with the same respondents. This discrepancy has been considered in the process of analysis and presentation of the findings in this paper.

Procedure

All counsellors within the charity use CORE-10 as a continuous measurement of psychological distress. Data were collected between 2014 and 2016 resulting in 158 responses; each taking approximately five minutes to complete, and causing minimal disruption to counselling time through evaluation. The number of CORE-10 forms does not represent the number of counselling sessions received but their stage of counselling as noted above: 'assessment', 'first', 'during' and 'final'. In addition, the pre-counselling phone call allowed comparison of scores with clients before and after the intervention.

All CORE-10 forms were sent to a central location at the end of each financial year and analysed by a research team using Statistical Package for the Social Sciences (SPSS).

CORE-10 scores were averaged by the number of clients who completed a form at each stage and any decrease in score shows improvement. Only complete data sets were used in this study (158) from a total of 616 clients. Incomplete sets do not necessarily indicate drop-out. Attrition rates were recorded at 371; measured by no forms completed from a certain session onwards. This could indicate the therapy was unhelpful, but could be due to problems such as transport issues or, in the case of these participants, treatment or end of life. Reasons for absenteeism were not recorded and this is therefore a limitation of the findings.

The counselling service consists of qualified counsellors (employed, sessional and volunteers) and student counsellors. Counsellors are qualified to a minimum of Postgraduate Diploma in Counselling, and are members of the British Association of Counsellors and Psychotherapists (BACP). The counselling experience of qualified counsellors ranges from recently qualified to over 10 years. The service uses a Brief Therapy Model, where counselling is planned around six sessions, though there are rare instances where there may have been more sessions undertaken. The main theoretical approaches used are Cognitive Behavioural Therapy, Psychodynamic, Humanistic/Person-Centred, and Brief/Solution-Focused Therapy.

The forms were completed by hand at the beginning of the counselling sessions. All counselling clients were advised that completion of CORE-10 forms was voluntary. Opportunities were made for the client to voice questions or concerns as to the use of the data with the relevant information set out in a contract, a copy of which was signed and kept by the client. It was made clear by the counsellor that the purpose of the data was to measure the effectiveness of counselling for research and evaluative purposes though, when deemed appropriate, it was also used as a potential therapeutic tool by the counsellor to show any decline in levels of distress to the client as sessions progressed.

Whilst clients were made fully aware that scores were not a reflection on themselves, the counsellor or the process itself, it is possible that bias may have occurred, for example, because some clients may have wished to please the counsellor by recording a drop in their levels of psychological distress. This is addressed further in the limitations of the study section. To discourage bias, all participants, both clients and counsellors were anonymised in the evaluation with only trends being reported on. All counsellors taking part in the study were anonymised due to the sensitive nature of individual evaluation within the organisation; meaning there are no links between the data and individual counsellor.

Participants

The charity counselling team provide counselling services to approximately 400-500 adults affected by cancer in Wales each year. Clients are commonly referred by healthcare professionals; including oncologists, clinical nurses, or members of the charity's staff providing another service; most commonly financial advice. Clients are contacted by a member of the counselling team within two weeks of initial contact with the charity. Clients are then allocated a counsellor who will arrange appointments and measure impact using CORE-10. As participating counsellors were anonymised on the CORE-10 form, their different types of counselling technique are not captured in the data.

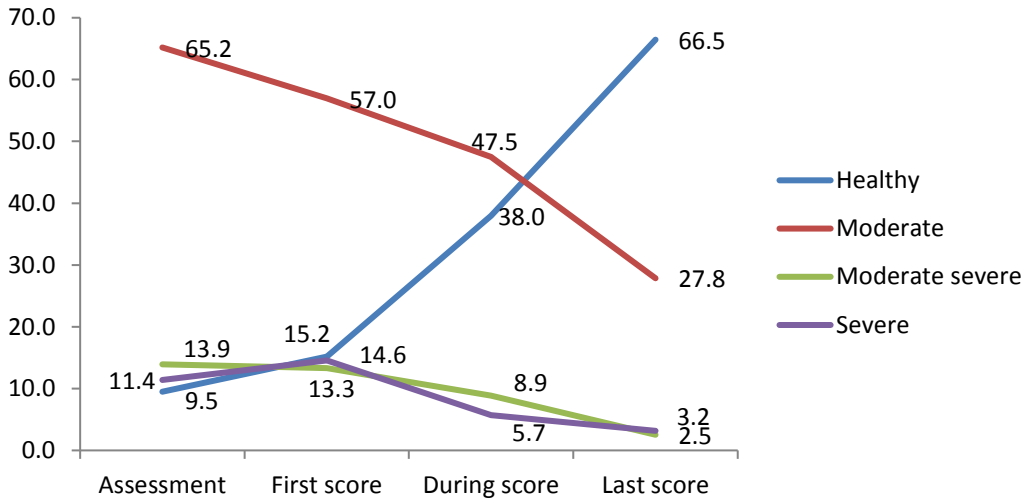
Participant ages ranged from 21 to 86 with a median age of 33 and mean age of 53. Most participants were between 51 and 60 (57) years old and the lowest between 21 and 30 (3) and 81+ (3). 126 (80%) participants were female and 32 (20%) were male. No other demographic information was requested beyond the CORE-10 requirements outlined above, to cause minimum disruption to counselling recipients. Each client waited approximately one month between 'assessment' and 'first' sessions, and thereafter, sessions were weekly or fortnightly.

Results

Psychological distress improved after counselling. Scores improved most significantly between 'first' and 'second' session with a 22.8% increase in patients scoring 'healthy'. This is compared with an increase of only 5.7% 'healthy' patients

between ‘assessment’ and ‘first’ session, before counselling had been received. Between ‘assessment’ and ‘first’ score, there is a moderate improvement from 9.5% reporting a healthy score up to 15.2% by the ‘first’ session. This score then accelerates significantly to 38.0% by the ‘during’ score and 66.5% by the final score. Interestingly, the ‘severe’ score rises from 11.4% to 14.6% between ‘assessment’ and ‘first’ session. Once counselling starts, this decreases to 5.7% at ‘during’ and then 3.2% at ‘final’ score.

Figure 1: Change in percentage of clients in each category



Overall 58.2% (92) went from the clinical (11+) to non-clinical (0-10) score range between their first and final session. 32.3% (51) remained clinical, 7.0% (11) remained non-clinical and 2.5% (4) went from non-clinical to clinical.

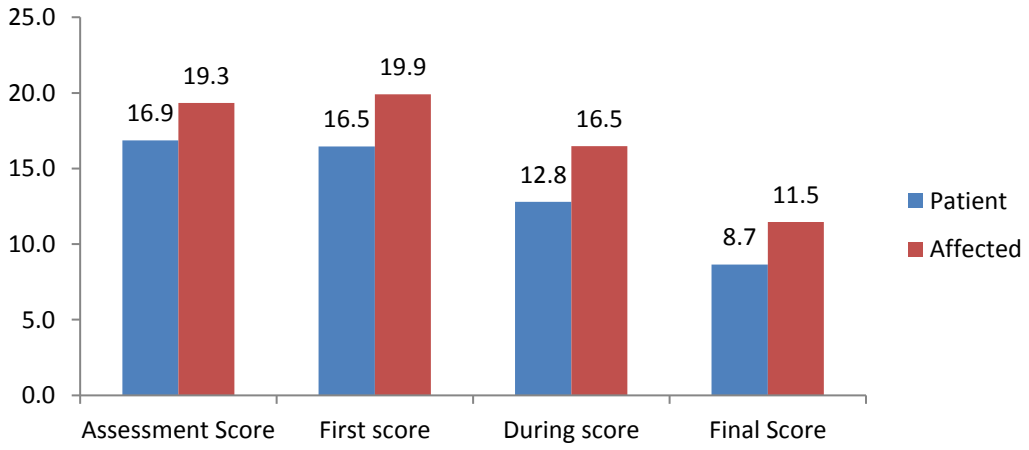
Comparing cancer patients and people affected by cancer

This section of the paper presents results from analysis separating people *with* and *affected* by cancer. 78% (118) of the sample group were people who had received a cancer diagnosis termed here 'patient', 22% (33) were either caring for a cancer patient or bereaved due to cancer, termed here 'affected'.

Table 1: client numbers by 'cancer status'

Counselling Client	**N**	**%**
Patient	118	78.1
Affected	33	21.9
Total	**151**	**100**

Figure 2: CORE-10 scores for patient and affected groups



In Figure 2 the patient group shows greater improvement in levels of psychological distress. Between 'first' and 'last' counselling session the affected group's score drops 7.8 points while the patient group's score drops 8.2 points, meaning an

improvement in psychological distress for both groups but more so for patients. Additionally, it seems that counselling not only accelerates the reduction of psychological distress but initiates improvement as psychological distress appears to worsen between ‘assessment’ and ‘first’ session and then to improve once counselling begins.

Male and female comparison

Most counselling clients were female (80%) and all CORE-10 scores have been averaged at each stage. Additionally, the common difficulty of encouraging men to attend counselling is acknowledged. Both genders show similar improvement between ‘first’ and ‘final’ sessions; however, females show more improvement than males between ‘assessment’ and ‘final’ with a drop of 17.8 to 9.2 (-8.6) compared with 15.4 to 9.9 (-5.5) for males.

Amongst females, between their first and final session, 61.1% (77) moved from the clinical (11+) to non-clinical (0-10) score range, 31.7% (40) remained clinical throughout, 11.1% (14) remained non-clinical throughout and 1.6% (2) went from non-clinical to clinical. Among males, between their first and final session 46.9% (15) went from the clinical to non-clinical score range, 34.4% (11) remained clinical throughout, 12.5% (4) remained non-clinical throughout and 6.3% (2) went from non-clinical to clinical.

Figure 3 below shows the average score by gender for each point in the data collection. Figure 4 shows the average change in scores between each point. Females start with slightly higher levels of distress than males but recover at a faster pace once counselling begins. However, if we look only at the change between 'assessment' and 'first' session, female scores decrease slightly while male score increase. Here we see an increase in psychological distress among men who are not receiving counselling, which is not the case for women. This could imply that the assessment session acts as a form of reassurance for women, but not for men. Therefore, it is possible to argue that for men the counselling triggers improvement, while for women the promise of counselling has a similar effect.

Figure 3: average score by gender

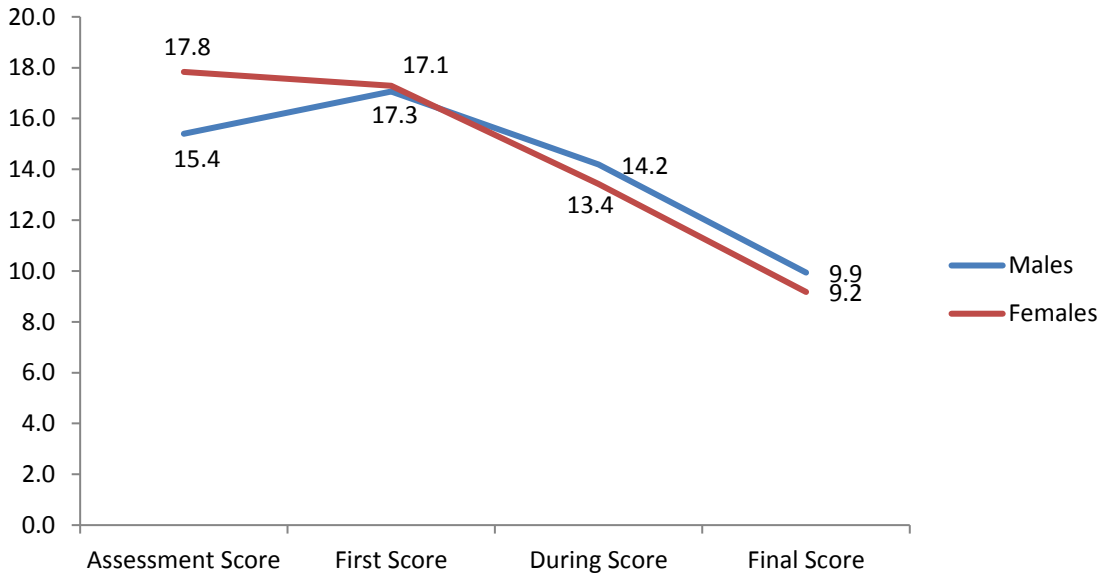
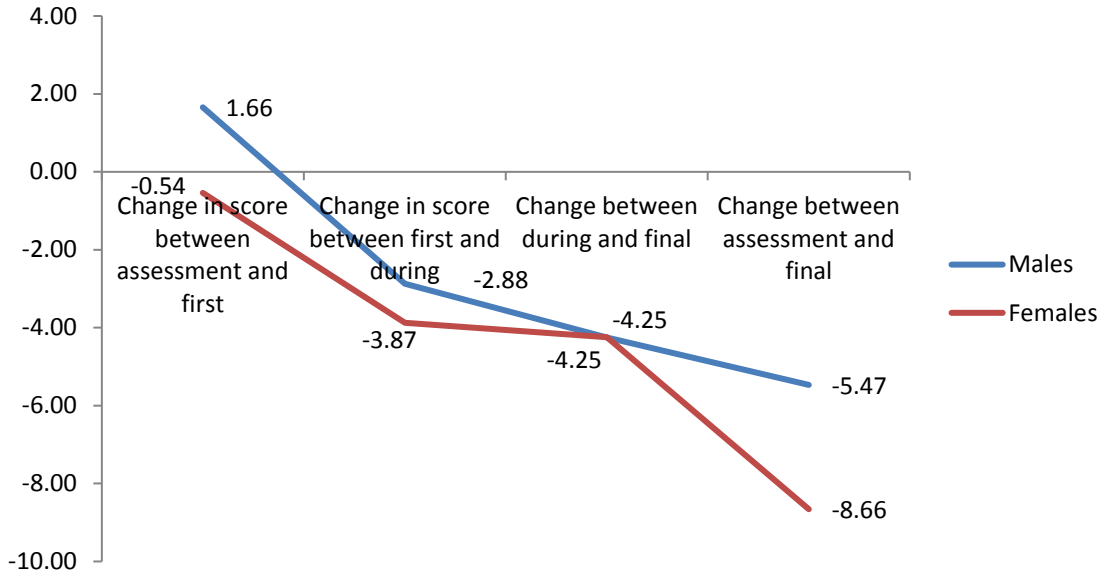


Figure 4: average change in scores by gender



Age comparison

Figure 5 and 6 below show the score and then change in score by percentage, this time by age.

Figure 5: average score by age

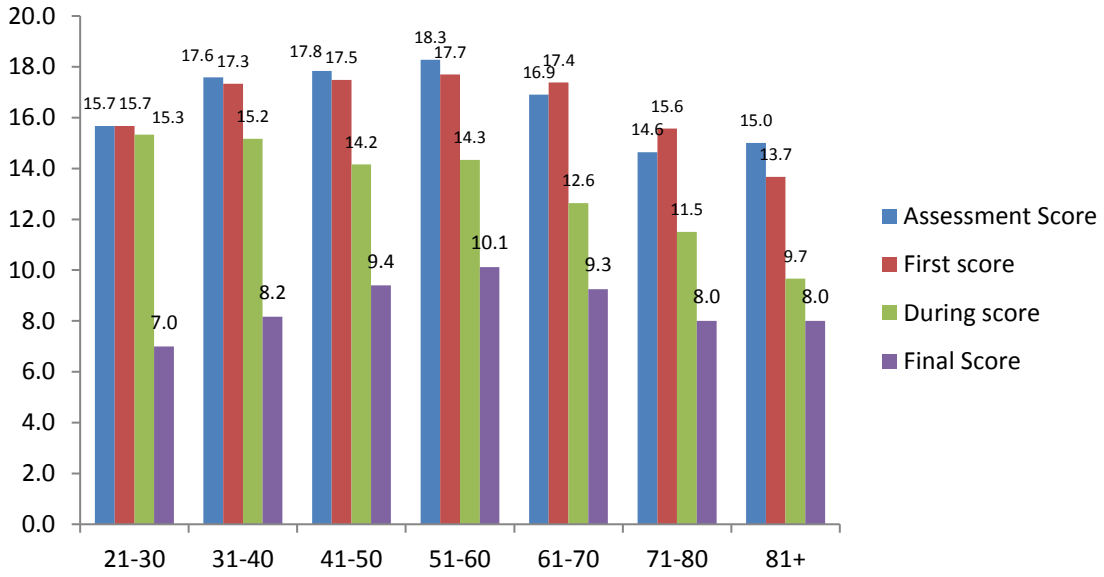
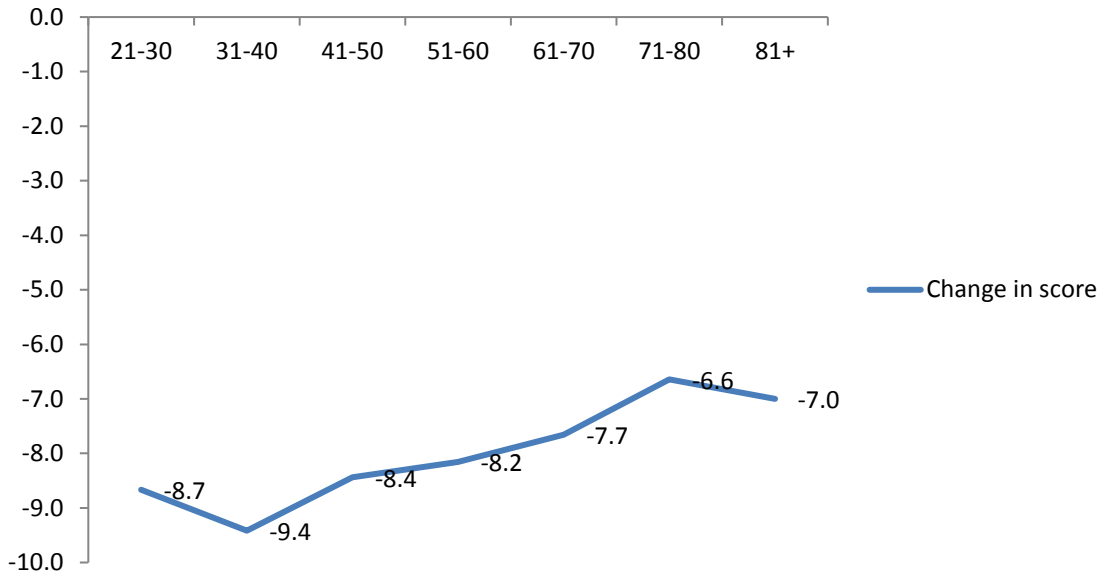


Figure 6: change in score by age



In Figure 6 all average scores have reduced with the biggest reduction among those aged 31-40 and the smallest among those aged 71-80. Counselling

becomes steadily less effective after age 40 up until age 81 when score reduction improves.

Discussion

Principal findings

There are three principal tentative findings in this research. Firstly, counselling outside a healthcare setting appears to be beneficial for all clients who receive four counselling assessments, regardless of cancer status, gender or age, with a caveat in the form of those who dropped-out for the process after the assessment. This could support the potential benefit of a referral system from health professionals to third sector services. The reduction in levels of psychological distress for patients and those affected by cancer add to research showing counselling to be more effective that routine primary healthcare (Hill, Brettle & Jenkins' 2008). As the counselling intervention took place post-treatment, it adds to Watson, Denton, Baum, & Greer's (1998) work showing counselling to reduce distress caused by diagnosis. Finally, in terms of Sharpe, Walker et al.'s (2014) work, this study adds psychological distress to the list of issues that counselling has been found to improve (depression, anxiety, pain, and fatigue).

Secondly, those affected by cancer improved more through counselling than those diagnosed with cancer. When considering the support in place through the NHS for patients, this finding highlights the importance of also supporting those *affected* by a cancer diagnosis. The psychological needs of this group could potentially be

overlooked within the healthcare service because the priority is treating those with cancer. Therefore, we suggest that an accessible counselling service with multiple referral routes outside a healthcare setting for both groups is beneficial. This finding adds weight to Grunfeld et al.'s (2004) research into family caregivers, showing the psychological and practical impact of caring for someone with cancer. The result from this study both echoes their findings but highlights a need for counselling among those affected by cancer and the potential improvement in psychological distress that counselling can bring about.

Finally, patterns by age and gender are seen in counselling outcomes, indicating a potential need for evidence-based tailoring of recruitment processes. As male participants scores worsened between 'assessment' and 'first' session, before receiving counselling, it indicates the importance of counselling for men and the possible prioritisation of shortening waiting times between 'assessment' and 'first' session in general. This finding adds studies into the impact of counselling on people with cancer (Watson, Denton, Baum, & Greer, 1998; Bloom and Gottheil, 2007; Sharpe et al., 2014; Ohlen, Holm, Karlsson & Ahlberg 2005; Omylinska-Thurston & Cooper's 2014), and those affected (Pitcealthly & Maguire 2003) do not distinguish between age and gender.

Strengths and weaknesses of the study

The main strength of this study is the fact that the research was carried out in a non-clinical setting using effective evaluation tools to produce research findings. In

this way, it bridges the gap between research and practice. It also addresses a significant gap in research, examining the impact of counselling for people affected by cancer outside of a healthcare setting. Therefore, the results have important implications relevant to those working within a healthcare setting and counselling specialists working in the community.

There are four identified limitations within this research. First, the counsellors involved in this study use a range of counselling approaches, and the different techniques have not been captured in analysis due to the small number of counsellors involved in this study and issues of anonymity. Different counselling techniques could affect differences in scores and changes to these scores and this has not been controlled for. Second, only using CORE-10 excludes the measurement of any outcomes beyond psychological distress. For the cancer patients in the study more specific issues related to their diagnosis and treatment may have been explored during counselling. For example, the physical effect of treatment on body image or bodily function; relationships with people in their lives or fear or relapse. For those affected by cancer, more practical issues may also have been a bigger problem than psychological distress, for example the financial burden discussed by Grunfeld et al. (2004). Qualitative data to identify potential contradiction between participant perceptions of counselling and CORE-10 score, as identified by Burke (2013) would overcome this limitation. Fourth, bias in the completion of the form, for example clients reporting lower scores to please the counsellor, encourage themselves or reporting high scores to secure additional

counselling sessions. Finally, dropouts and reasons for discontinuation of CORE-10 form completion have not been recorded or included in analysis for comparing the data of those who had completed a full counselling course. Consequently, those who may have left the service due to a perceived lack of effectiveness are not included. Future studies of this type may benefit from including those who did not complete the course of counselling.

Future Research

While CORE-10 is an effective tool for measuring counselling outcomes in relation to the six CORE domains, the issues faced by people with cancer are likely to be more nuanced than the information reflected in this study. Further qualitative research is needed into the impact of counselling with representatives from these groups.

Counselling outside a healthcare setting is shown here to improve physiological distress for those diagnosed with or affected by cancer, although benefits vary by demographic group.

In this study collaboration between third sector cancer support providers and the NHS had beneficial outcomes for those receiving the counselling service. Further research into the wider benefits of this type of collaboration and any links with the positive outcomes would be welcomed by the authors.

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